S.H. Sundstrøm responds

New cancer drugs that have a documented effect and market access in Norway, but are still awaiting assessment by the Decision Forum, put oncologists in a difficult situation from an ethical standpoint.

Cancer therapies that have been introduced in recent years, such as precision medicine and immunotherapy, can transform incurable cancer into a chronic disease. With such therapies, some patients can add years to their lives, while their ability to work and quality of life are maintained. The Decision Forum must ensure equal treatment and correct prioritisation, but the long lead times for processing of cases place a burden on the system. Time is the scarcest of resources for cancer patients. It should come as little surprise that some of these patients want the best available treatment and are willing to purchase it from private institutions. The cost may quickly run into NOK 1 million.

The Norwegian Oncological Association has requested a clarification regarding the duty to inform about cancer drugs that have market access in Norway and have been ‘put on hold’, but may provide significant benefit to the patient. The association first raised the issue with the Norwegian Medical Association’s legal experts in 2015, and later in debates with politicians responsible for health, and in the media. Nobody – not the lawyers, not the bureaucrats, nor the politicians – has given any indication of what is deemed appropriate.

My statement to the effect that I assess the patient and his or her assumed financial situation to decide what kind of information to provide was the subject of a complaint to the Medical Ethics Council of the Norwegian Medical Association and the County Medical Officer of Sør-Trøndelag county. My first reaction was surprise, but I have later welcomed the complaint, with a view to the need for debate and a clarification of practice.

In their articles, both the Medical Ethics Council and the Clinical Ethics Committee (KEK) at St. Olav's University Hospital conclude that it is not up to the doctor to assess their patients’ ability to pay, and that the doctor is obligated to provide information on other forms of treatment that may deemed effective (1, 2). Furthermore, as I interpret the answers that I received from both the Medical Ethics Council and the Clinical Ethics Committee at St. Olav's University Hospital, such information should be volunteered even when not actively solicited by the patient. I accept the criticism on the question of my assessment of the patient's potential ability to pay. I nevertheless remain uncertain as to whether it is ethically more correct to volunteer information on private treatment options that might be effective. Is it ethically more correct to subject a patient to 'pressure' to purchase private treatment that might wreck havoc with the family’s financial situation than to refrain from doing so? I argue that ‘each and every one of us must decide for him- or herself how to
comply with the duty to inform. This must be done with due consideration and discretion. The key issue should be to provide information that causes patients and their relatives to feel that they are seen, heard and cared for’ (3).

I believe that there can be no single correct answer to this dilemma, but in my opinion, compliance in line with the above quote will be ethically acceptable.

REFERANSE:
